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ABSTRACT

This feature issue newsletter looks at issues the self-advocacy movement is raising and the contributions it is making to the lives of people with developmental disabilities. Articles by self-advocates and advisors to self-advocacy organizations talk about their self-advocacy experiences, barriers to self-advocacy, and ways to support it. Primary articles have the following titles and authors: "Self Advocacy: Realizing a Dream" (Tia Nelis); "The History and Accomplishments of 'Self-Advocates Becoming Empowered'" (Perry Whittico and Terry Ingram); "'Citizens in Action': Self-Advocacy and Systems Change" (Walter Rupp); "A Self-Advocate's Voice Heard on Federal Committee" (Liz Obermayer); "My Friendship with Sally: A Self-Advocate Becomes an Advocate" (Nancy Ward); "Barriers to Support: Waiting Lists" (Beverly El-Afandi); "When the Student Is Ready, the Teacher Enters" (Mary F. Hayden); "Wanted: Empowerment Fanatics" (Ruthie Marie Beckwith); "Guidelines for Providing Information to Self-Advocates" (Marci Chaikin); and "Self-Advocates and Advocates: Voices for Continued Change" (Bob Williams). A list of five videotapes and ten print materials is also provided. (JDD)

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ED 371 515

IMPACT

INSTITUTE ON COMMUNITY INTEGRATION
COLLEGE OF EDUCATION
UNIVERSITY OF MINNESOTA

Feature Issue on Self-Advocacy **Volume 7 (1) Spring 1994**

Eleven of the sixteen National Steering Committee members for the organization Self Advocates Becoming Empowered, along with local chapter advisors, at the committee's January, 1994, meeting. See story on page 2.

Self-Advocacy: Realizing a Dream

by Tia Nelis

Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn responsibilities. The way we learn about advocating for ourselves is supporting each other, and help each other gain confidence in themselves to speak out for what they believe in.

- Definition of self-advocacy approved at the 2nd Annual People First Conference, September, 1991.

Self-advocacy is up and moving. Right now people with disabilities are coming together to learn how to advocate for themselves and to teach others that we can make decisions and choices for ourselves. We want to be treated like everyone else and to be given the same choices and chances that other people without disabilities have. We don't want to be labeled or put away any more. We want to learn about speaking out and how to get the support we need to live, work, play, and be a part of our community.

Right now a lot of self-advocates are coming together to form a coalition to help people with disabilities across the United States. As more and more people start getting involved and forming self-advocacy

Self-advocacy continued on page 15

From the Editors

An organized self-advocacy movement is growing among people with developmental disabilities. This movement - which many view as a civil rights movement - signals a fundamental change in the self-perception of people with developmental disabilities and in the relationship between persons with disabilities and service providers, policymakers, and families. This issue of *IMPACT* looks at the issues the self-advocacy movement is raising and the contributions it is making to the lives of people with developmental disabilities.

According to a recent study, an estimated 11,600 persons with disabilities are involved in the self-advocacy movement in the United States. There are over 500 active self-advocacy groups in 43 states and the District of Columbia.* More and more people with developmental disabilities are claiming the right to direct their own lives.

In these pages is an inside view of this emerging, grassroots movement. There are articles by self-advocates and advisors to self-advocacy organizations. They talk about their self-advocacy experiences, barriers to self-advocacy, and ways to support it. It is our hope that in reading these stories you will also embrace the belief that all people have the right to exercise control over their own lives.

* Data from *The Self-Advocacy Movement by Persons with Developmental Disabilities*. See Resources, page 14 of this *IMPACT*.

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EC 303 102

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The History and Accomplishments of *Self-Advocates Becoming Empowered*

by Perry Whittico and Terry Ingram

About 400 people went to Estes Park, Colorado, in September, 1990, for a five day national self-advocacy conference. At that conference people were deciding on whether there should be a national self-advocacy organization. There were workshops that got people prepared for the idea. There were a number of meetings about the idea after the traditional conference hours. We broke up into five regions of the country and we elected two representatives for each region, except for the Pacific region. The Pacific region decided that they needed to strengthen their region before they could join, and they didn't feel that the movement was ready for a national organization. Toward the end of the conference the majority voted to give the elected representatives a year to come up with a working paper to support the idea of a national organization.

In May of 1991, the National Steering Committee got together in Schaumburg, Illinois, and talked about how to create a national organization. They voted to recommend several suggestions, such as to develop a mission statement and definition of self-advocacy, to have an organization that would be a coalition of state and local self-advocacy groups that vote for regional representatives to be on the steering committee, to work on five major issues, and to have nine regions of the country with two representatives from each region. They also recommended that each region should have specific responsibilities, like getting funding, identifying legislation, and developing a newsletter. The steering committee developed a booklet of ideas and recommendations, and the University of Minnesota printed it in time for everyone who was going to come to the next conference to get one. It was in the form of a ballot.

We had another national conference at the Stouffer Hotel in Nashville, Tennessee, in September, 1991. At that conference the people elected in Colorado presented their work from the past year and asked the participants to vote on their recommendations. There was still some discussion about what we were doing because there were many new people at the conference who had not been present for the discussions in Colorado. A number of states who had not wanted to be involved in Colorado came on board in Tennessee. We voted on the recommendations and they were passed. Then we had a new election for steering committee representatives. Nine regions met and elected 17 people and quite a few alternates. We count this as the time when the national organization was born.

Over the next year we were trying to raise funds so that we could meet to discuss ways to continue. We had several conference calls and learned that conference calls with so many people are very frustrating. It was hard to get anything done because it was hard to hear everyone and understand the ideas being presented. Sometimes several people would try to talk at once, and other people didn't talk at all. We all agreed that we needed to meet face-to-face instead of over the phone. The other problem we had was that none of us knew each other. We all lived in different states and it was hard to remember who the other members were, even if we had met them a couple of times at a conference. Finally, we had a call where we decided to have a meeting. By then we had collected enough money to get together one time, and had written a grant to allow us to meet a second time.

Our first steering committee meeting was in Nashville in December, 1992. Sixteen members and eight advisors came to that meeting. We elected officers, decided on committees, and decided which members and advisors would serve on which committee. We also chose a name for the organization: Self-Advocates Becoming Empowered.

Our first meeting was hard for us because we knew little about each other. It seemed like it was chaotic because none of us had ever started a national organization before. Ideas flew rapidly around the room, but our chairperson, Nancy Ward, took hold and steered it in an organized direction. Alliances formed between different members, and we started getting to know each other. We figured out that we had to work together, but it was hard at first. For instance, we realized that we had made a mistake in holding elections for offices right away because three people had not arrived yet when we voted. These three felt that they did not get a chance to run for office or vote. Finally we decided that we would keep the officers we had elected until we wrote our by-laws. That taught us that we need to make our decisions as a whole group, and that's how we have operated ever since. We have all learned from the mistakes we have made and have learned to work as a group.

In April, 1993, thanks to the grant we got from the Johnson Foundation, we were funded to come to the Wingspread Conference Center in Racine, Wisconsin. The conference center provided organized meeting times, meals, lodging, and hospitality breaks. They also provided social time so we could get to know each other. The Wingspread staff was very helpful and would get anything that we truly needed. Nancy Ward and the other officers had developed an agenda ahead of time. Part of that agenda included a talk by Justin Dart, who came to present us with an award from the President of the United States and to encourage us to keep up the work we were doing. He promised us support from his office, where he was Chair of the President's Committee on

Employment of People with Disabilities. He has been sending us information ever since.

Another part of the agenda was a team-building session, which was a discussion and exercises on how to work together as a team. The first exercise was a poster of people who were whitewater rafting, and we were asked to decide where we would be on the raft. Two representatives decided that they were the waves that were trying to capsize the raft! We enjoyed the team-building session, and we learned a lot about ourselves. For example, we found out that we had similar goals and that we were making a good start toward working together as a group. We found out more about what we had in common.

Other things we did at this meeting were to decide that the next national conference would be in Virginia, decide that we would submit a grant to the Kennedy Foundation to fund future meetings, and discuss ways of saving money. We also nominated Liz Obermayer to the President's Committee on Employment of People with Disabilities. It was a really productive meeting.

We had a short meeting before the Third International Self-Advocacy Conference in Toronto in June, 1993. Our major accomplishment at that meeting was to decide that People First of Tennessee would take care of our finances until we incorporated and had federal tax-exempt status. We also used our team building skills to tackle our difficulties and used more trust and fewer motions.

In July, Nancy Ward met with President Clinton, along with the representatives of several other disability organizations. This was both an honor and a way of recognizing that our organization is important and should be included whenever decisions affecting our lives are made.

We achieved more in October, 1993, when we met again in Nashville. We created some new committees, wrote bylaws, talked a lot about the next elections of new representatives, talked about the national conference being planned for northern Virginia, and recommended some changes to the conference program. We also created a newsletter insert and decided to accept the Kennedy Foundation grant that we had just received. With this grant we will have to develop a statement on our ideas about community living. We were very busy with committee work and with our work as a group.

We would say that the people in the National Steering Committee have diverse skills and are trying our best to make a strong contribution that can be carried on by others.

Perry Whittico is a self-advocate with Self-Advocates of Central New York, Syracuse, and Terry Ingram is a self-advocate with People First of North Carolina, Willowsprings.

Self-Advocates Becoming Empowered: An Observer's Perspective

Self-Advocates Becoming Empowered is a relatively new national coalition or network of local and state self-advocacy organizations. It aspires to represent people with developmental disabilities. It is, in fact, an organization whose members and leadership are such people. It is based on the principle that people, all people, have the right to speak for themselves.

One of the early meetings of the 18-member steering committee of the organization was held at the Wingspread Conference Center in Racine, Wisconsin, in April 1993. Wingspread is known throughout the world, and thousands of people of recognized achievement have attended conferences there in the past 35 years. I am a program officer for The Johnson Foundation, which operates Wingspread, and was the foundation staff person responsible for this meeting.

I have been working at Wingspread for 18 years and have observed hundreds of conferences. This was the most memorable, however, in part because it contributed to my own education and in part because it stretched my own assumptions about what people are capable of.

Like some other meetings at Wingspread, this one went fairly slowly. I think one reason was that the conference participants were pioneers – that is, they were inventing a new national organization, never an easy task. Another reason was that the members of the steering committee went to great pains to treat their colleagues with courtesy and sensitivity. But probably the principal reason the conference developed slowly was because the conferees had not previously been allowed the opportunity to speak for themselves. For them this was a relatively new experience. The perhaps trite words "empowered" and "self-advocates" took on immense resonance for me.

I am a student of Mexican history, and one of my heroes is Benito Jaurez, an Indian who became president of his country in the 19th century. His best known words are "El respeto al derecho ajeno es la paz," which in English means, "Respect for the rights of others is peace." It is a basic principle that rights are inherent – that is, that everyone has certain rights, that everyone has the right to dignity and respect, that all people have the right to speak for themselves. All people.

Contributed by Richard Kinch, Program Officer, The Johnson Foundation, Racine, Wisconsin.

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Citizens in Action: Self-Advocacy and Systems Change

by Walter Rupp

In any given legislative session, at least a dozen pieces of legislation are introduced affecting the lives of persons with developmental disabilities. Bills concerning the closing of state institutions; the ways the State funds, delivers and evaluates services; and proposed major changes in special education are examples of just some of the legislation introduced during the Minnesota Legislature's 1993 session. A great deal of legislation is proposed and passed, policies are made, and services are designed or changed, often without the direct input of the people most affected, which in this case are persons with developmental disabilities. Influencing public policy is often time-consuming, complicated, and difficult. But it can be done and is being done by members of Advocating Change Together, or ACT, a disability rights and self-advocacy organization in St. Paul, Minnesota.

Since its formation in 1979, ACT has influenced policies affecting persons with developmental and other disabilities, using the legislative and rule-making process and direct-action organizing as vehicles to effect systems change. In this manner, ACT has won important victories for people with developmental disabilities, including the establishment of employee councils in sheltered workshops and the passage of Rule 40 governing the use of aversive and deprivation practices in residential programs.

In 1991, ACT formalized its objective of influencing policymaking and achieving systems change by creating a program called Citizens in Action. The program addresses the great need to get people with developmental disabilities involved in the systems change process by providing education on policy formation, the legislative and rule-making process, the importance of grassroots participation, and the self-determination skills required to participate effectively at the systems level.

ACT members also use the program to develop new leadership and strengthen existing leadership in the self-advocacy movement. People new to self-advocacy benefit from the program's strength in teaching self-determination skills, or what ACT refers to as personal self-advocacy skills. The skill areas addressed here include assertiveness, decision-making, problem-solving, interpersonal communication, negotiation, and rights and responsibilities. More experienced self-advocates serve as trainers in teaching these skills, as mentors to newer self advocates, and as community organizers, reaching out to people with developmental disabilities in their communities and encouraging them to speak for themselves. In short, the program works to support individuals in developing personal self-advocacy skills in order to become actively involved in systems self-advocacy.

Richard Mathison, the current President of ACT's board of directors, illustrates the success of the Citizens in Action program with his involvement in self-advocacy. Since developing personal self-advocacy skills through ACT, Richard has become involved with systems self-advocacy through providing public testimony; calling, writing, and meeting with legislators on issues connected with disability; and through his leadership role on the employee advisory council at his place of work. Richard was also involved in ACT's development of a video-based self-advocacy training curriculum, and has used this material at workshops, self-advocacy conferences, and at his church. In teaching others about self-advocacy, Richard is strengthening his leadership skills and helping to voice the concerns of people with disabilities.

Several members of ACT and other participants in the Citizens in Action program have formed a Governmental Affairs Committee, targeting specific issues affecting people with developmental disabilities. The group of experienced self-advocates comprising this committee decides which issues to monitor, which ones to support, and on which issues to initiate action. In 1993, the committee collaborated with other disability rights groups to better the local paratransit system, and met with legislators about the reauthorization of the Rehabilitation Act and the Developmental Disabilities Act. On these issues, as well as those of case management, rehabilitation, employment services, and the use of aversive and deprivation practices in group homes, ACT members have participated significantly at the systems level by bringing the perspective of persons with developmental disabilities to the rule-making process.

Through the Citizens in Action program, ACT has identified several issues including state and federal health care reform and the closing of large public and private institutions as issues to pursue in 1994. As part of these efforts to effect systems change through public policy, ACT is developing a Citizens in Action curriculum. The curriculum will be available to self-advocacy groups interested in becoming involved in systems change and can serve as a resource to groups currently working at this level.

The Citizens in Action program has grown rapidly since its inception. In showing that the personal is the political this program has helped self-advocates have a stronger voice in the formation of public policy and to effect broader systems change.

Walter Rupp is Community Organizer for Advocating Change Together, St. Paul, Minnesota.

A Self-Advocate's Voice Heard on Federal Committee

by Liz Obermayer

I am on the President's Committee on Employment for People with Disabilities. The national organization, Self Advocates Becoming Empowered, has elected me to be their representative on this committee. I think it is very important for me to be a member for two reasons. First there will always be a " voice" from the people who are receiving the services. Second, just having me there shows that it is another step towards winning the "fight" against discrimination.

The President's Committee on Employment for People with Disabilities is a committee that recommends viewpoints on different issues relating to employment for people with disabilities to the President of the United States. Some of the issues that the committee talks about include health care, discrimination on the job, and educating people about working with people that may have problems on their jobs due to their disabilities.

My first meeting was in November. It was very exciting. At times during the meeting I couldn't believe that I was in the same room with some of the most powerful people in this movement. However, I thought about it and realized that I "played" and will "play" very important "role" at the meeting. The reason I say that is because I am the first self-advocate to be on this committee. Yes, there's a lot of people there with disabilities, but in a way self-advocates are different. This is true because we have been fighting for our rights for all our lives. Most of the rest of them became disabled through accidents or childhood disease.

At this meeting, one thing that made me think that I made a difference was around the upcoming conference that the committee will sponsor in the spring. We talked about how important it was for self-advocates to attend. I pointed out to them that most self-advocates can't afford to go. In the past, the committee has not helped self-advocates with expenses. They are beginning to discuss some other possibilities to change this.

I am very proud and honored to be on the President's Committee on Employment for People with Disabilities. I hope that this is just the beginning of inviting self-advocates to be on committees such as this one. After my term is up, hopefully the committee will ask me to recommend one of my fellow self-advocates for appointment to this committee.

> ...just having me there shows that it is another step towards winning the "fight" against discrimination.

Liz Obermayer is a member of the President's Committee on Employment for People with Disabilities, and a self-advocate with People First of South Jersey in Voorhees, N.J.

Self-Advocates Monitor Services

OK-AIM (Oklahoma Advocates Involved in Monitoring) visits people with developmental disabilities who live in the community to check on their quality of life. About half of the monitors are secondary consumers (family members) and about one-third are primary consumers. This article describes the experiences of three of the primary consumers.

• James Meadours

I decided to become a monitor because I used to live in a group home. I have experience in how a group home operates because I know how people should be treated fairly, the right amount of care and assistance they need, and how staff should work in that environment - what their responsibilities are. Also, I know what areas the staff needs to work on with the individuals. I know what to expect quality of life to be in a group home.

Sometimes it's frustrating when things don't look right. One time I visited a supported living arrangement. One of the people was non-verbal. Staff told me that he pretended to be sick to get out of work. I thought that if he was smart enough to figure out how to fake being sick to get out of going to the workshop, he was smart enough to learn to use a communication board. But when I asked staff about it, they said he wasn't smart enough to use one. It made me feel angry inside - how staff perceives people like ourselves.

I think people like ourselves should have the same opportunities as everyone else. Sometimes agencies and staff are afraid of consumer monitoring - they're afraid something bad is going to happen. If we can judge apples and oranges, we can monitor our own services to see if people have what they need.

Monitors, continued on page 15

My Friendship with Sally: A Self-Advocate Becomes an Advocate

by Nancy Ward

To understand this article, you first have to understand that my friend Sally had cerebral palsy and because of this she had a lot of spasticity, used a wheelchair, and could not speak. But, I only saw her as Sally, my friend. She definitely had the personality that one should "not judge a book by its cover." Sally was a tiny person, only weighing 88 pounds. She was 28 years old and had short brown hair and big, brown, expressive eyes. Sally had a big smile that would reach to her eyes. She had a mischievous spirit and though she couldn't talk, she had a deep laugh that made me feel good and laugh with her.

I started taking Sally out into the community - going to movies, out to eat, and shopping.

I first met Sally in a nursing home. I was paid to feed her. The more I got to know her, the less desire I had to be paid. I finally declined payment because Sally had become my friend. Sally had some difficulty in understanding why I wanted to be her friend. She'd only known family and paid staff relationships.

A lot of times because she could not talk people thought she was dumb. Sally communicated by nodding her head "yes" or "no." This sometimes requires asking several questions to determine what she wanted or needed. Some people would ask me what I got out of our relationship because she couldn't talk. My response was that in order to understand the relationship, you had to see us together.

Sally lived in a small town before going to the nursing home where she had lived for several years. I started taking Sally out into the community - going to movies, out to eat, and shopping. Some people would stare at her and make her feel self-conscious. When she became uncomfortable with the stares, her spasticity became worse. And because she was trying to tell people to quit staring at her, Sally started yelling, the only sound she was able to make. I took her back to the nursing home and taught her social skills. I learned a valuable lesson in this. If I'd have taught Sally some social skills first, she would have known how to act in the community and it wouldn't have embarrassed her.

After awhile I asked her if she wanted to live out in the community in a group home. She didn't understand or know what I was talking about. I explained it to her and when we would go out we'd go by the different group homes for her to look at. She finally decided that this would be a good idea.

This whole process of teaching her social skills and helping her decide if she wanted to live in the community took three years. We also needed to convince her parents that living in the community was a good idea. This took another three years. Finally Sally moved into a group home where her self-esteem increased because she was part of a family again. Her parents and I both felt she would continue to grow into her own independent person.

Then, for some reason, her mom and I were not allowed to see her anymore. So I asked my friend, Lyn, Executive Director of Regional Programs, to go with me to see Sally. It helps to have friends in high places. When we went in to see her she was down to 44 pounds and had been left in bed the whole time. She had bedsores all over. I told Lyn that we needed to get her out of this group home. "Where will she go?" was Lyn's question. We gave the staff two weeks to improve Sally's quality of life. On the day I was to return, I was told that Sally was not there so I didn't need to come.

She'd turned blue the night before and was taken to the hospital. I went to the hospital and talked to Lyn about having her move to another group home, but because of the bureaucracy the service system had, she had to go back to her original group home.

This whole process of teaching her social skills and helping her decide if she wanted to live in the community took three years.

We finally worked it out for her to go into another nursing home. In order for her to be admitted into the nursing home, she would have to get a "G" tube inserted into her stomach, which would take away the one thing that brought the most pleasure to Sally: her ability to enjoy her food. Because it takes her so long for her to eat, this was the only time she was able to spend with others. Then she would look at you with those big brown eyes full of expression asking, "Why is this happening to me when I was told that living in the community was going to be so good?" This really got to me because I had no answer.

The one good thing that came from her having to move back to the nursing home was that the ARC-US was going to have its national convention in Omaha, Nebraska. I knew that it would be very difficult to get Sally to be able to go with me so I worked on this for a whole year. The first thing that was thrown into my face was the cost of her medical needs. She needed 24-hour care. Lyn agreed to cover the

medical care she needed. The nursing home just kept finding different excuses for not allowing Sally to attend the convention. So I kept coming up with ways to eliminate their excuses until they had none left. Sally got to attend the national convention in Omaha.

One of the things I liked about her going with me was she was able to overcome her institutionalized behaviors that she was starting to show again. At the convention she only had one outburst. She had only one because people were starting to treat her as a person again. Another thing that I liked about Sally going to the convention was that her mom got to spend time with her in an ordinary setting without all the tubes and wires. And we fed her meals that she thoroughly enjoyed.

That same year I got the citizenship award and I feel that a lot of my self-advocating skills were because of the friendship I had with Sally. We had a dance afterwards and guys took her out of her wheelchair and danced with her. This meant a whole lot to me.

Sally eventually moved to a medical unit in Omaha, which is a home that is staffed by nurses. So, Sally was part of a family again. And she had a place that she could call her home. One night staff went in to check on her and she was doing okay; the next time they went in to check on her she wasn't doing okay. So they called 911 and by the time they got there, Sally had died.

Another one of my friends and I work at a camp every year where we teach senior high school students how to interact with people who have disabilities. Two of the kids made us friendship bracelets. I gave my bracelet to Sally. At Sally's funeral, Sally was buried with a friendship bracelet. I feel that my friendship with Sally is the most valuable friendship I ever had because how often do we tell people we like something when we don't. Sally couldn't do this because she couldn't talk, so her reactions were honest and sincere. And this has helped me grow in my relationships with other people.

Nancy Ward is a self-advocate with People First of Nebraska, Lincoln.

Kammie Barfield (standing, left) and her family members.

My Experiences in Self-Advocacy and My Family's Role in Helping Me

I'm the President of People First of Ruston, Louisiana. This organization was formed in 1983 by a group of people with mental and physical handicapping conditions who wanted their opinions heard concerning the type of services and treatment they were receiving. Its members include individuals who live independently, in large residential institutions, in community residential programs, and with their families. People First of Ruston provides training for members on self-advocacy and their right to participate in the political process.

In 1983, I was living at home with my parents and started working at a sheltered workshop for handicapped people. This agency helped me get a supported employment job at a college cafeteria in 1986.

At that time I moved into a group home and lived there for three years. This was because the group home provided the transportation to my job. Leaving home and learning my job was hard for me, but the job coach helped me to understand the rules and regulations on a job.

When I had free weekends my parents would come and get me to go home to visit. This helped me to keep in contact with my family, which was very important to me. My parents were kept informed about my progress and my training in the group home and in learning to live on my own. When change needed to be made in my job and the group home training, my parents and I were included in the decision making.

In 1990, when the time came, I moved out of the group home into independent living and shared an apartment with a friend for about six months. At this time I was working at a nursing home. Since I was a diabetic and had seizures, many difficulties arose and I had to move back home with my parents.

I'm still living at home and helping with chores there. My parents provide transportation to M.R.C. Industries Workshop where I work on the Self-Advocacy Becoming Empowered Committee and People First meetings. I go to church and social activities with my family. At this time I am unemployed, but hope to be placed in a suitable job in the future. My parents will help with transportation and support in adjusting to a new job.

Contributed by Kammie Barfield, a self-advocate and President of People First of Ruston, Louisiana.

Barriers to Support: Waiting Lists

by Beverly El-Afandi

Angela Burton is a vivacious 23-year-old woman who graduated from high school in 1991. In one way she is very typical of many young adults with mild mental retardation who exit special education programs upon graduation: she is "waiting" for community services.

Angela's educational program had attempted to prepare her for integration into the community, providing vocational training prior to her graduation. According to her mother, Angela had enjoyed school, never wanting to miss a day. She had many friends there. But in discussing her school experience, Angela said, "They always put me on work instead of helping me with reading or math, which were really hard for me. I was not too happy because I had to go to work." The school had felt that job skills needed to hold a higher priority than academic skills for Angela. Angela and her mother recently began working on a reading skills program at home; learning to read is still "difficult", but for Angela it is an important goal.

Angela Burton, one of many individuals with disabilities on waiting lists for services and supports.

Angela has been out of work for about 18 months. She lost her job a month before her family moved from the city to a suburban home. When asked about her life and daily routine, Angela said, "It's boring. I really don't do all that much. I watch TV. I do the laundry, and sometimes I dust or vacuum while Mom is at work. I sleep a lot." When asked if she ever feels depressed, Angela replied, "Yes, I do, a lot. I get cranky and take it out on my mom and dad and sister. I get cranky often, but today is not too bad. I'm expecting company later, so I am getting excited about that."

Other than her boyfriend, whom she met seven months ago while rollerskating with her family, Angela has made no new friends since moving. Her family's home is relatively isolated, with few nearby neighbors. Angela said that in the past she had met friends at school or work. She does not see them anymore because, "I took the city bus from where I used to live, but I do not know how to get there now."

Since her family's move they have been waiting for her service records to be transferred from their former county to their new county. Angela had received supported employment services in the former county following graduation. Her educational transition plan had included referral to a community service provider for the needed ongoing services. When she graduated, Angela worked at a fast food restaurant, but later had requested a different job. She had secured employment in the housekeeping department at a local hotel. It was a job she had enjoyed. Angela said, "I made a lot of friends on the job. It was great! The first time I walked in, they joked with me. I miss them." Deciding to attempt to live more independently, Angela had also moved into an uncle's home while working at the hotel. She lost her job at the hotel when she began to call in ill frequently. Angela said, "I was having problems with my seizures, so they fired me because of that. I told them I cannot work mornings, because it is really hard for me with these seizures going on. I have to have a night job instead of working mornings, because mornings do not work. They said, 'Well, you've got to work mornings at the hotel.' I said fine. I did not say anything else. I tried to tell them, but they never listened."

Angela also admitted that there may have been other reasons for the problems that arose when she attempted to live and work more independently. She had missed her family a great deal, and also said, "I did not have my cat there either, so I probably would have wanted to move back home because I was missing my cat, too." Angela plans to take her cat with her when she is able to move to her own apartment. She also feels that she is older and more mature now, and will be able to call her mother on the telephone when she feels lonely.

In the future, Angela would like to get a small apartment in a secured building - one with "locks on the outside doors." Ideally, it would be on a bus line somewhere near her job, and where her boyfriend Tim would be able to come and visit her. Tim's friendship is very important to her. Weekly activities such as going to the movies or the tractor pulls or just "sitting around watching TV" with him and her family currently constitutes her social life.

If Angela were to move to her own apartment, she stated that she would need, "someone to help me pay my bills and in getting to the grocery store. I cannot do that by myself." Though she does know the alphabet, and once, when lost, used that knowledge to spell out street signs over the telephone so that her mother would know where she was, she is unable to read, but would like to learn.

While Angela hopes to live independently some day, her most important goal now is to find a job. When she moved with her parents to the suburb, she and her mother had gone to the local social service agency to change her

Medical Assistance and to request assistance in finding a job in her new situation. They were told by the social worker that later visited them in their home that Angela's name would be put on a waiting list for supported employment and transportation services, but that nothing was currently available. Nearly 18 months later, Angela is getting impatient. "I really want to go back to work. It is boring here. There is really nothing to do. The only thing that I am concerned about is that they are not helping me with a job. It is really bugging me!"

Angela had always been encouraged by her family to be involved in decisions regarding choices that will affect her life. They encouraged her to take an active part and to be involved in the school program planning process. Angela said, "I was there. I told them what I wanted. I tried, but they never listened to me. They said just go for jobs." Angela also tried to advocate for herself later in dealing with the agency providing her supported employment services. She said, "I tried to tell them, but my mom was not there at that point. I told them I cannot work mornings because it's real hard for me. I tried to tell them, but they never listened."

Angela had made the decision to move to her uncle's home while working at the hotel. She wanted to live more independently. She also made the decision to return to live with her family when she felt overwhelmed by the responsibilities involved. It is true she consulted with her family, but she felt that the decision was hers. Angela indicated that she felt that by taking the risk of leaving her family home she had learned things that will help her in making better plans before she moves out again. She has recently requested that information regarding the People First organization be sent to her. Both she and her mother feel that a self-advocacy group could enhance Angela's skills and range of friendships. For now, however, the job is "the most important thing."

Angela Burton lives in Cottage Grove, Minnesota. Beverly El-Afandi is a Research Assistant at the Research and Training Center on Residential Services and Community Living, University of Minnesota, Minneapolis.

The Barriers I Face in My Environment

My name is Mary Lou Ebel. I was born with cerebral palsy. I have a speech impediment, spasticity and I use a wheelchair. Because of these disabilities I face many barriers.

One of the barriers is that I was unable to be evaluated for a job in the community. I went to Voc Rehab to be evaluated. The type of testing that was done was to determine what type of job I would like to do or would be good at. But they didn't have enough knowledge to give me the kind of support I needed to complete the testing. While I was there, a friend was called to take me to the restroom because the evaluators were not comfortable with helping me. This made me feel like I wasn't even a person in their eyes. After the morning was over, they told me that because I have severe disabilities I was too disabled to be evaluated. I thought they were supposed to work with persons with severe disabilities. They said that they were supposed to have so many clients evaluated per month and placed in employment opportunities within the community. This barrier has caused me not to be able to work at a job within the community. I would like to have a job in the community so I could make more money to support myself.

I work in a workshop, but I get very frustrated sometimes when I feel I don't get enough money for the contracts I do. Or I don't have contracts to do at all. Or no one comes up with a jig for me to do the contracts that the workshop already has. So I just sit there.

Another barrier is the social barrier. When I would go on breaks at work I would have no one to talk to. When I socialized after work, I had to go with everybody whether I wanted to or not because we only had one staff person. I had to go to the sports event when I would have rather gone to the movie.

Sometimes transportation is a barrier. I need to use the accessible public transportation to get to work. I have to ask someone to order a van two weeks ahead of time for the time slots I need to go to work. So if the van is not ordered to pick me up, I don't have a way to work. Or if someone else gets the time slot I need, then I don't have transportation to work.

The workshop that I work at now sometimes doesn't have any contracts at all. People get very bored just sitting around. And because residential staff would have to be paid to give us support, we cannot stay at home.

Because of all these barriers I have to face in my environment I have had to learn how to speak out for myself through my Individual Program Plan and just in advocating for myself at work. I have learned to develop my self-advocacy skills through my involvement with People First. My self-advocacy skills are important to me because they have helped me work through some of these barriers.

Mary Lou Ebel is a self-advocate with People First of Nebraska, Lincoln.

When the Student is Ready, the Teacher Enters

by Mary F. Hayden

"We still need to teach professionals and others about how people with disabilities would like to be treated. I hope the self-advocacy movement will continue with people with disabilities teaching others about how they can work together as a team and help each other out." As I first read these words written by Tia Nelis, a self-advocate with People First of Illinois, I thought to myself that she is right. Many of us who are professionals, service providers or parents need to learn how people with disabilities want to be treated rather than assume that we already know how they want to be treated. Many of us do need to learn to work together as a team, rather than "working for" or "on behalf of" individuals with disabilities. Yet, I wonder, how many of us are ready and willing to be students and to learn from teachers with disabilities?

The self-advocacy movement intends to shift power from professionals, service providers, and parents to individuals with disabilities. Self-advocates are already making strides toward empowering themselves. New self-advocacy organizations continue to form and the established organizations continue to grow in numbers and strength. The self-advocacy movement is here to stay. As it continues to grow and gain rights for its members, professionals and others will need to learn a new way of doing business. The question among professionals, service providers, and parents becomes, "How do we become ready to learn a new way of interacting with individuals with disabilities?"

I believe we need to first look at our motivations. In my opinion, the most dangerous motivation is the desire to save people, or the "I Only Have Good Intentions" syndrome. Those who suffer from this syndrome have engaged in a range of behaviors that have denied persons with disabilities their basic rights. Some of these behaviors range from placing people in large, segregated residential settings; supporting forced sterilization; denying people the right to vote, to marry, and to work for regular wages; deciding what type of services and supports someone will receive without talking to the individual; or making day-to-day decisions for the person (e.g., when to go to bed, when to eat, what to wear, how money will be spent, what social activities will be attended, or what food to buy). As Mel Ash, Buddhist priest and author, once said, "The only difference between a halo and a noose is the distance of twelve inches." To be ready to learn a new way of relating means that we are willing to periodically search our souls for unintentional pitfalls that may lie within us.

To be ready to learn also means to be willing to look to others who can teach us. I think that professionals, service providers, and parents can learn much from the model of respect and teamwork found in Self-Advocates Becoming Empowered, the national organization of self-advocates. In discussions and decision making, members of this organization respect everyone's opinions; take as much time as is needed to understand each person's views; share equally in the work; focus on the vision of the organization, rather than the advancement of an individual; celebrate their successes; and learn from their errors without apology. This is a model where people collaborate rather than dominate, and where all voices are heard.

We can also observe the new way of relating in the interactions between advisors to self-advocacy groups and the members. The role of advisors, as articulated in the publication *Spreading the Word* published by Speaking for Ourselves, includes assisting, listening, guiding, staying in the background, acting as a role model, nurturing potential leaders, and helping members do things themselves. It is a model of supporting people in the manner in which they desire to be supported as they work out their own destinies.

However, the most important way we can make ourselves ready to learn is to form friendships and professional relationships with people who have disabilities. For some professionals and service providers it is hard to get to know self-advocates and build trust, especially when the individual speaks in ways that may be hard to understand. Through my own experiences, I realize that my difficulties in this type of situation are centered around my discomfort in being unable to understand an individual's speech or their thought process. I have found that when I am willing to accept and own my discomfort, my ears open up. I have also found that self-advocates are more than willing to help us understand.

I often think that if professionals and service providers put as much effort into listening as self-advocates put forth to be heard, this alone would do much to help us let go of the burden of thinking that we must have all the answers and all the power. Rather than "talking about" or "deciding for" people with disabilities, we would listen to and learn from people with disabilities as they talk about what they desire for their own lives. And in this new role we would stand alongside people with disabilities, as equals, supporting them in the way in which they want to be supported and learning from them the lessons we need to learn.

Mary F. Hayden is Research Director with the Research and Training Center on Residential Services and Community Living, University of Minnesota, Minneapolis, and an advisor with Self-Advocates Becoming Empowered.

Wanted: Empowerment Fanatics

by Ruthie Marie Beckwith

Ten years ago, Dennis Heath, one of the original advisors with People First International, came to our first annual conference. He came at the invitation of Tennessee self-advocates who wanted to learn more about the beginning of a self-advocacy movement they had only witnessed on a 16mm film. Dennis shared his thoughts about the movement and demonstrated how to motivate individuals with disabilities. Members of the audience shared their own individual thoughts, experiences, and ideas. They celebrated the accomplishment of planning and carrying out a large training event that culminated in the birth of a statewide organization. After the conference, Dennis stayed to chat with our first state president and myself about self-advocacy in general. He helped us affirm our roles as leader and advisor.

A lot has happened since that first conference. Our state organization has grown to over 40 chapters and 1,060 members. Nationally, 43 states now have self-advocacy efforts. However, one of the greatest challenges of developing and supporting the self-advocacy movement remains: recruiting advisors for local self-advocacy chapters.

The role of advisors has remained essentially unchanged since the beginning of the self-advocacy movement. Advisors fill two critical roles: supporting local and state self-advocates and developing community organizing expertise. Providing support is a key element of the empowerment process. Self-advocates (new recruits and veterans) require logistical assistance and personal support in carrying out the work their chapters embrace. Specific supports provided by advisors include basic help with transportation and reading, and encouragement to set increasingly challenging goals. Advisors also help members work through personal problems that fall outside the realm of the chapter's work, but result in personal empowerment and longterm friendships.

Developing community organizing expertise is another critical area addressed by advisors. Advisors provide assistance in developing membership organizations and strategies for promoting longterm results. Advisors help local groups recognize and prioritize issues collectively. Finally, advisors work to expand the leadership roles available to self-advocates within the movement and without.

Nationally, there is a broad range of individuals who serve as local and state advisors. Many have roots in service provision; others come from broader social justice fields. All who appear to endure, however, have one underlying characteristic: an unshakable belief in the self-determination of persons with disabilities as a distinct community.

Advisors who serve in the self-advocacy movement have all experienced "misinterpretations" of their roles as they carry out their work. They are frequently accused of manipulation, coercion and exploitation. The emerging leadership of the movement has proven to be the best defense against these "misinterpretations." Leadership that is clearly organized and committed to self-determination is the end product of advisors' efforts.

Advisors to local and state self-advocacy groups are a rare breed. They work as invisible agents of empowerment. At their best, they facilitate great personal and collective changes within a significantly disenfranchised community. They employ a broad range of creative ideas and strategies to accomplish the development of a strong community. They recognize and embrace the individual worth and abilities of all.

The need for local and state advisors has increased as the self-advocacy movement has expanded. Enlisting is relatively simple. Contact a local self-advocacy chapter. Express a commitment to empowerment. Be ready to give and receive support. Develop your own organizational skills and those of persons with disabilities. Brace yourself for an ongoing transformation of your belief system from a perspective of dependency to interdependency. Finally, place an order for empowerment fanatic business cards and pass them out to your friends and colleagues.

Ruthie Marie Beckwith is staff advisor with People First of Tennessee, Nashville, and an advisor for Self-Advocates Becoming Empowered.

What Do Advisors Do?

Being an advisor is hard work. You wonder if you are doing it right. There is always the question of "Am I doing too much or not enough?" According to self-advocates, it's important for advisors to:

- Support people
- Assist in meetings
- Listen
- Help plan agendas
- Help people organize
- Guide in new situations
- Call officers and members
- Be a friend
- Stay in the background
- Answer questions when necessary
- Keep chapter a 'safe-place'
- Act as a role model
- Give ideas and suggestions
- Create opportunities for learning
- Nurture potential leaders
- Help people do things themselves

Adapted from *Spreading the Word* (1993), a publication of Speaking for Ourselves, Plymouth Meeting, Pennsylvania.

Guidelines for Providing Information to Self-Advocates

by Marci Chaikin

When contacted about writing this article, my first thought was to graciously decline. I tend to resist anything that includes the word "guideline" or tells me how to do something. However, I felt I had a professional responsibility to consolidate what I have learned as advisor to People First of Hamilton County, so what follows are "parameters" that have guided me:

- Always work from the premise that people with developmental disabilities can understand. I can't count the number of times I have given presentations to professionals who immediately decide that the people they serve are simply not capable of speaking out for themselves or making choices in their lives. We, as professionals must be open minded and work from the assumptions that people with developmental disabilities want information, are capable of understanding information, and that it is our job to ensure their comprehension.
- Include people with disabilities in developing the information that will be disseminated. If I am going to develop anything for people with disabilities, then I have to do it with the expertise of people with disabilities.
- Communicate like a "real" person. Forget the professional jargon and big words. Sometimes I say that I have a dual personality. When in the professional arena I communicate accordingly, and when working with people with developmental disabilities it is also necessary that I make a shift in the way I speak and/or write.
- Provide information in a variety of formats, including written and audio. Because of the diversity of people with developmental disabilities there is no set format for presenting information. Even if something is written in a very simple manner, this does not ensure that everyone will understand. When I prepare information I write simply and concretely. I also incorporate clip art or icons that are associated with the words. If needed, I provide the material on audiotape. When presenting information, be flexible.
- No matter what format you use, support must be available to assist in "processing" the information. As previously stated, there is no way to present information that will be accessible to all people. There must be personal contact to explain, problem-solve, and answer questions.

Providing information that is accessible is complex. However, people we serve have the right to understand information that will help them and we, as professionals, have the responsibility to support this.

Marci Chaikin is advisor to People First of Hamilton County, Cincinnati, Ohio.

Supporting Self-Advocacy with Information

My dream is for people with disabilities to be able to speak out for their rights anywhere in the world. To do that, self advocates need to receive information in a way that they can understand what is being said. Some of the things that I think are important in sharing information are these:

- I like to have information ahead of time, like before a meeting, so I can learn it and have time to think about my opinion.
- The best way to get information to me would be by videotape because you can understand videos really quick and you can see what's going on.
- With written information it helps to have pictures because they help people know what it means and make it easier to remember. It also helps to use the same pictures so people know what it means each time they see it (like $ for money).
- It is easier to understand written information if you get the sentences down to a few for each idea. Large print is also important because it is easier to read.
- It is also good to put a square around or highlight important information.
- If there is a lot of written information, papers should be given out a little at a time so people won't skip over information because it is too much to read.
- It is important for me to get the person's address and phone number so I can ask them questions about stuff I don't understand.

I hope these ideas help you get information to self-advocates in a way they can understand. Then they will be able to tell you what they think about what's going on and be able to speak up for themselves.

Joe Pichler is a self-advocate with People First of Alaska and a member of the Governor's Committee for Employment of People with Disabilities.

Self-Advocates and Advocates: Voices for Continued Change

by Bob Williams

Opportunities for people with disabilities across the United States have never looked better. Looking back at our formidable history, we have challenged the status quo and have achieved many important milestones together: the closing of several institutions, broader access to education, the rise of employment and economic independence, home-ownership opportunities for people with disabilities, family support, and the passage of the Americans with Disabilities Act (ADA), just to name a few. We did not achieve these milestones by accident. People with disabilities and advocates, both individually and as a consortium, have advocated, demanded change, educated themselves and others, and have established a firm foundation in the disability policymaking process.

People with disabilities and advocates - individually and as a consortium - have advocated, demanded change, educated themselves and others, and have established a firm foundation in the disability policymaking process.

While the nuts and bolts of policymaking may appear to be a daunting task, many people with disabilities and advocates have ignored the impossible blockades and have rolled up their sleeves to achieve what is possible. They've participated in leadership training; strategized through family support groups; worked with the media; attended conferences; educated state legislators, community leaders and school administrators; and some have testified before the U.S. Congress about their needs. Milestones have been achieved because people with disabilities and advocates have played an integral role in forming disability policy.

One such milestone we can all proudly point to is the passage of the Americans with Disabilities Act. The ADA is setting a new tone and direction in our nation. I grew up in a time when the presumption was that it was my problem if I could not get into a building or my neighborhood school. What the ADA has done is to turn that presumption around to now reflect our rights under this law.

Yet, despite these accomplishments, there are many issues to be debated and new voices to be heard. The intricate public policy role that people with disabilities and advocates have played in the past must now be reinvigorated and must encompass new ideas, new individuals, new thoughts and creativity.

Some time ago, a Harris poll revealed that although Americans with disabilities generally have a greater interest in politics, we do not turn out to vote or otherwise get involved. The number of people with disabilities not registered is approximately 17 million. I believe that there are a number of reasons for this.

Historically, polls and registration places have been inaccessible. As a community we are poor, we are marginalized, and we are in the infant stages of political organization. In addition to having disabilities, many people - many young people especially - have learned to be passive. They have learned that the world will come to them. They have learned how to be helpless. We have to break through that and take control of and responsibility for our lives. What we need now is a new give and take in today's debates. People with disabilities must give of themselves and take more power over their own lives.

A few debates have been won. Most debates are still evolving. One such debate is that of health care reform. The disability community offers a unique perspective on the health care debate. Health is seen as the absence of disease and disability. We in the disability community know that is wrong. Health is about the ability and the support to be independent and productive. I believe this definition makes for a much more meaningful debate for us and for the nation.

Another important evolving debate is on personal assistance services. There is a need for more people with disabilities to get personal assistance so they can function in the mainstream. While many people with disabilities may have more opportunities, many cannot take advantage of them. President Clinton is very aware of how the lack of personal assistance not only robs people of our ability to live and work, but robs the nation as well.

There are many exciting milestones yet to be achieved. It is through the knowledge, experience, and solutions offered by people with disabilities and advocates that will continue to help establish sound disability policy. Every voice counts!

Bob Williams is Commissioner with the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, Washington, D.C.

Resources

■ Videotapes

- **Four Easy Pieces**. A training package, including a videotape, that teaches four basic areas of self-advocacy: assertiveness, solving problems, knowing rights and responsibilities, and participating in committees. Available from Advocating for Change Together, 1821 University Ave., Suite 363 S., St. Paul, MN 55104 • (612) 641-0297.

- **Our Voices Count: Self-Advocacy Now!** A videotape about self-advocacy in general. Available from The Self-Advocacy Association of New York, 75 Morton St., New York, NY 10014 • (212) 627-2104.

- **Self-Advocates of Indiana**. A videotape about self-advocacy in general, and a handbook describing how to start and support a self-advocacy group. Available from Arc Industries, 4919 Projects Dr., Fort Wayne, IN 46825 • (219) 482-8587.

- **Sticks and Stones.** A documentary on the self-advocacy movement in Minnesota. An excellent video for seeing self-advocates in action. Available from Advocating for Change Together, 1821 University Ave., Suite 363 S., St. Paul, MN 55104 • (612) 641-0297.

- **Voices That Count, Making It Happen: A Presenter's Guide**. This videotape shows people with developmental disabilities as leaders and partners on boards and committees. It also shows the types of supports self-advocates may need to be members. Available from University Affiliated Cincinnati Center for Developmental Disorders, 3300 Elland Ave., Cincinnati, OH 45229 • (513) 559-4639, TDD (513) 559-4626.

■ Print Materials

- **Self-Advocacy Resource List**. An annotated bibliography of publications. Available from Arc- U.S., 500 E. Border St., Suite 300, Arlington, TX 76010 • (800) 433-5255.

- **Self-Determination Resource List**. An annotated bibliography of publications. Available from Human Policy Press, P.O. Box 127, Syracuse, NY 13210 • (315) 443-4338.

- **Leadership Plus**. A training manual addressing fundamentals of meetings, roles and responsibilities of consumer representatives, and applying knowledge as a committee member. Available from Arc Tulsa, 1400 S. Boston, Suite 650, Tulsa, OK 74119 • (918) 582-8272.

- **People First: Advice for Advisors**. A guidebook for advisors to self-advocacy groups. Available from People First of Canada, Kinsman Building, 4700 Keele St., Downsview, Ontario M3J 1P3, Canada.

- **People First: Leadership Training Manual**. A booklet about starting and supporting self-advocacy efforts. Available from People First of Canada, Kinsman Building, 4700 Keele St., Downsview, Ontario M3J 1P3, Canada.

- **Speaking Up for Yourself and Others: Some Ideas for Successful Self-Advocacy**. A booklet teaching people about self-advocacy organizations and how to create successful organizations. Available from People First of Nebraska, 521 South 14th St., Suite 211, Lincoln, NE 68508 • (402) 475-4407.

- **Spreading the Word**. A booklet developed to help people learn about self-advocacy. It is written for members of self-advocacy groups to use together. Available from Speaking for Ourselves, One Plymouth Meeting, Suite 530, Plymouth Meeting, PA 19462 • (215) 825-4592.

- **We Can Speak for Ourselves**. A book of practical advice about self-advocacy and the history of self-advocacy in Nebraska and England. Available from Brookline Books, P.O. Box 1046, Cambridge, MA 02238 • (617) 868-0360.

- **IMPACT: Feature Issue on Self-Determination**. This 20-page publication explores the relevance of self-determination for persons with developmental disabilities across the lifespan, and ways in which it can be encouraged. Written primarily for service providers and families. Available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

- **The Self-Advocacy Movement by Persons with Developmental Disabilities: A Demographic Study and Directory of Groups in the United States** (1993). By Nancy Longhurst. Available from AAMR Publications Center, P.O. Box 25, Annapolis Junction, MD 20701-0025 • (301) 604-1340.

Self-advocacy, continued from page 1

groups and learning, more people will start to notice that people with disabilities can give input and ideas to others. There are many people with disabilities still out there that don't even know about choices, rights or responsibilities. There are also a lot of people who don't get the support they need or the chance to be a part of their community or be treated like everyone else.

Even as we get more involved with self-advocacy and there are more leaders, we still have a lot of work ahead of us. We have taught people how to be a part of their community and we have given them the self-esteem they need to speak out. Yet, we still need to teach professionals and others about how people with disabilities would like to be treated. I hope the self-advocacy movement will continue with people with disabilities teaching others about how they can work together as a team and help each other. Both children who are growing up and adults who are aging need to learn about self-advocacy. That's why this is just the beginning of what we have to do so that others that follow behind will have self-advocacy training.

Both children who are growing up and adults who are aging need to learn about self-advocacy.

Self-advocates have accomplished a lot by being involved and learning about issues that affect people with disabilities at all levels. Some of the things we have accomplished are:

- People with disabilities learning about legislation.
- Getting the Americans with Disabilities Act passed.
- Starting self-advocacy projects in high school so students can learn at a young age.
- People who are aging starting to learn about the issues that affect them and learning that they can work on things to help them and affect their lives.
- People supporting and helping each other.
- Making friendships.

Like everyone else, we have a dream that some day people with disabilities will get the skills and support that they need to live happy lives. When this happens, people won't need to worry about not being treated like everyone else because they'll be treated as equals. Self-advocacy is very important right now for people to learn, but maybe someday we won't need it anymore because our dream will come true and people with disabilities will live happy lives.

Tia Nelis is a self-advocate with People First of Illinois, Wayne, Illinois.

Monitors, continued from page 5

• Joseph Meadours

I decided to be an OK-AIM monitor because I saw that people with disabilities needed to get out and see what other people with disabilities needed and help them. I thought at first that it was hard because I didn't know what to look for, but as I monitored I learned and it got easier. Now I look to see if the house looks pretty good for me to live in - that's how I judge.

People with disabilities are watching and helping other people. We can open a lot more doors. I enjoy meeting different people - with and without disabilities - and sharing experiences. It's great to go back to visit people a year later and see how much improvement they've made.

• Mark McCarver

I found out about OK-AIM when some of the monitors visited me. I thought it was a good idea so I requested to be a monitor myself. I got into it to give something back and to reassure parents that the programs are going to be good and that everything is going to be all right. I don't like feeling like I'm snooping around in people's homes, but I guess it's something we just have to do for people to be safe. That first visit was kind of scary, but the other monitors were so friendly that they made it a lot easier. Looking back at how much monitoring I've done through the years, it's a lot of fun. So, I like going as much as I can. I enjoy getting to meet different people and help them get the things they need, like if they need a talking device maybe our input will help them get it.

Being a consumer monitor has turned out to be as good as I thought it was going to be. It's useful because I get to tell people about self-advocacy. It's also good to check on people. And you get to meet people that you knew from awhile back.

Contributed by James Meadours, Joseph Meadours, and Mark McCarver of OK-AIM, a project of People First of Oklahoma, Tulsa.

Self-Advocacy is...

Gaining *confidence* in yourself to:

Make friends and participate in activities.

Grow in ability to help yourself and others.

Work together to make services better for people with disabilities.

Contribute to the community.

From *Speaking Up for Yourself and Others: Some Ideas for Successful Self-Advocacy*, published by People First of Nebraska, October, 1993.

In this issue . . .

- Self-Advocacy: Realizing a Dream
- A History of *Self-Advocates Becoming Empowered*
- Self-Advocacy and Systems Change
- A Self-Advocate's Voice Heard on Federal Committee
- Self-Advocates Monitor Services
- My Friendship with Sally: A Self-Advocate Becomes an Advocate
- My Experiences in Self-Advocacy and My Family's Role
- Barriers to Support: Waiting Lists
- The Barriers I Face in My Environment
- New Roles for Families, Service Providers, Professionals
- Wanted: Empowerment Fanatics
- Guidelines for Providing Information to Self-Advocates
- Supporting Self-Advocacy with Information
- Self-Advocates/Advocates: Voices for Continued Change
- Resources

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Managing Editor: Vicki Gaylord
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The mission of the Institute and Center is to improve the quality and community orientation of professional services and social supports available to individuals with disabilities and their families. Inquiries about the Institute or IMPACT can be directed to: **Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • (612) 624-4512.** IMPACT is available in alternative formats upon request.

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Institute on Community Integration

109 Pattee Hall
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University of Minnesota
Minneapolis, MN 55455

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